nephron
Clinical
Practice

Nephron 2017;137(suppl1):103–116
DOI: 10.1159/000481366

Published online: September 29, 2017

UK Renal Registry 19th Annual Report: Chapter 4 Demography of the UK Paediatric Renal Replacement Therapy Population in 2015

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Keywords
Adolescents · Aetiology · Children · Demography · Established renal failure · Incidence · Prevalence · Pre-emptive transplantation · Renal replacement therapy · Survival · Young adults

Summary

- A total of 941 children and young people aged <18 years with established renal failure (ERF) were receiving treatment at paediatric nephrology centres in 2015.
- At the census date (31st December 2015), 75.3% of prevalent paediatric patients aged <16 years had a functioning kidney transplant, 13.0% were receiving haemodialysis (HD) and 11.7% were receiving peritoneal dialysis (PD).
- In patients aged <16 years, prevalence of ERF was 62.7 per million age related population (pmarp) and incidence was 10.2 pmarp.
- The most common primary renal diagnosis was renal dysplasia ± reflux, present in 34.7% of prevalent paediatric patients aged <16 years.
- A quarter of patients aged <16 years had one or more reported comorbidities at onset of renal replacement therapy (RRT).
- Pre-emptive transplantation rates for children aged three months to 16 years who were referred early have been maintained and were 33.2% for the 2011–2015 period.
- At transfer to adult services, 89.4% of patients had a functioning kidney transplant.
- Survival during childhood among children commencing RRT was the lowest in those aged under two years compared to those aged 12 to <16 years, with a hazard ratio of 4.1 (confidence interval [CI] 1.7–9.9) and in those receiving dialysis compared to having a functioning transplant, with a hazard ratio of 6.5 (CI 3.4–12.6).

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Introduction

The UK Renal Registry (UKRR) publishes annually chapters detailing demographics, clinical, haematological and biochemical parameters for patients managed in UK paediatric nephrology centres. In the UK, care for children, adolescents and young adults with established renal failure (ERF) requiring renal replacement therapy (RRT) is a tertiary service provided in 13 paediatric nephrology centres. All centres are equipped to provide peritoneal dialysis (PD) and haemodialysis (HD), with 10 centres also undertaking kidney transplantation.

Young adults aged 16–18 years may be managed in either paediatric or adult services, depending on local practices, educational and social factors. In this report, data for all patients aged <18 years in UK paediatric nephrology centres reported to the UKRR (with a particular focus on the demographics of those aged <16 years) are described.

In the UK in 2014, the prevalence rate of treated ERF in children and adolescents aged <16 years was 60.4 per million age related population (pmarp) and the incidence rate was 9.4 pmarp [1].

The objectives of this chapter are:

1. To describe the UK incidence, prevalence, causes of ERF and modality of treatment of children, adolescents and young adults on RRT on 31st December 2015
2. To describe trends in (1) over the past 15 years
3. To describe pre-emptive transplantation rates and survival of children and adolescents on RRT aged <16 years in the UK.

All 13 paediatric nephrology centres in the UK contribute data to the UKRR, mandated in England by the NHS service specification which requires, ***'paediatric renal units to submit data comprising the national renal data set to the UK Renal Registry on all patients on renal replacement therapy'*** [2]. In most cases this is via an annual extract of a centre's clinical computer system which is checked, validated and loaded onto the UKRR paediatric database. Where this is not possible, data returns are completed using a data collection form and manually loaded. At each return, missing data items are sought. Centres pay a capitation fee in order to support the process. Currently, the UKRR paediatric and adult databases are maintained separately and a future merger is planned.

Methods

Centres arranged for their own data to be extracted and sent to the UKRR for processing by clinical informaticians. For this report, end of year numbers were required by 31st January 2016 and the full data by 31st March 2016. However, the last submission was received on 4th September 2016. Overall responsibility for the process is held by the chair of the British Association for Paediatric Nephrology (BAPN) Audit and Registry Committee.

The content and analyses contained in the paediatric chapters are discussed and agreed by the BAPN Audit and Registry Committee members.

In this report, patient groups are described as:

1. 'Incident' group: patients who started RRT between 1st January and 31st December 2015
2. 'Prevalent' group: patients who were receiving RRT on 31st December 2015
3. 'Five-year' groups: patients who started RRT in the periods of 2001–2005, 2006–2010 and 2011–2015.

RRT is defined as all patients with renal transplants and patients on HD and PD for 90 days or more, with dialysis for acute kidney injury (AKI) not reported upon at present. In this report those aged <16 years at start of RRT who had received at least 90 days of RRT are included. Data for those aged 16–18 years and those receiving RRT for <90 days are not currently uniformly submitted to the UKRR.

The populations used to calculate the incidence and prevalence were obtained from the Office for National Statistics (ONS) [3]. The mid-2015 population estimate produced by the ONS, based on the 2011 census, was used to calculate the 2015 incidence and prevalence; the 2003 census data were used for the 2001–2005 group, the 2008 data for the 2006–2010 group and the 2013 data for the 2011–2015 group. Incidence and prevalence for 16–18 year olds are not reported. This is because data would not be representative of the UK as a whole, because these young people may also be managed in adult services.

Ethnicity is defined as stated by the patient/family and is reported as White, South Asian, Black and Other. The 'South Asian' ethnicity includes those of Indian, Pakistani or Bangladeshi origin only. The 'Other' ethnicity includes those from Chinese, other South Asian groups, e.g. Vietnamese and Malaysian, Arabic, mixed race ethnic origin or any other group. 'Black' ethnicity includes those of 'Black-African', 'Black-Caribbean' origin and 'Black-other' groups.

Statistical analyses were performed using SAS 9.3, with group analyses using the chi-squared test and median analyses using the Kruskal-Wallis test. Infants under the age of three months and 'late presenters' (defined as those commencing dialysis within three months following first review by a paediatric nephrologist) were excluded from analyses when calculating pre-emptive transplantation rates. For survival analysis, only patients starting RRT between 1st January 2001 and 31st December 2014 and receiving RRT for at least 90 days were included to ensure a minimum of one year follow-up at the census date. These patients were followed up to a maximum age of 16 years. As the maximum age of follow-up was restricted to 16 years it was not possible to calculate 10-year survival probabilities for patients starting RRT aged over eight years, or five-year survival probability for children

starting RRT aged >12 years. A Cox regression model was used to calculate hazard ratios for patient survival, adjusting for gender, age at start of RRT and RRT modality as a time dependent variable. Survival probabilities were calculated using univariate Kaplan-Meier curves.

Results

Data returns

Centres used a variety of clinical data systems to facilitate returns. In 2015, the majority of paediatric renal centres were using Vitaldata (Birmingham, Cardiff, Glasgow, Leeds, London Great Ormond Street), with others using Clinicalvision (Manchester, Newcastle), Mediqal (Belfast, Nottingham), Proton (Bristol), CyberREN (Liverpool) or bespoke systems (London Evelina, Southampton).

Most centres submitted their 2015 data electronically ($N = 12$) to the UKRR via data extracts. The remaining centre used paper forms which were manually entered into the database.

Overall data completeness was excellent for the following: age and gender (100%), ethnicity (98.0%), start and 90-day treatment modality (99.7%) and start date (99.5%). Completeness of other data items ranged from 83.4% to 99.2% and is shown by centre in table 4.1. Centre size and type (if undertaking paediatric kidney transplantation) are also displayed.

The UK paediatric prevalent ERF population in 2015

A total of 941 children and young people aged <18 years with ERF were receiving treatment at paediatric nephrology centres in 2015 (table 4.1). Of these, 769 (81.7%) were <16 years of age. Table 4.2 shows the number of these patients receiving RRT and rate of RRT by age group and gender. There was more than ten times the number of teenagers than infants receiving RRT. The prevalence of RRT increased with age and was higher in males across all age groups with an overall male to female ratio of 1.7 : 1.0. The reported prevalence in <16 year olds was 62.7 pmarp.

Table 4.3 shows the prevalence of ERF in under 16 year olds by ethnicity. Children from ethnic minorities displayed higher RRT prevalence rates when compared with White children, with South Asian children exhibiting the highest rates.

Modality of treatment

The majority of prevalent paediatric patients under 16 years old in 2015 had a functioning transplant, as shown in figure 4.1. The ratio of living to deceased donor transplants was 1.0 : 0.8.

Forty-four percent of patients started RRT on PD, 33% on HD and 23% with a pre-emptive transplant, as displayed in figure 4.2.

Analysis by age shows the proportion of those receiving dialysis as current treatment was higher in younger children, with increasing use of transplantation in older

Table 4.1. Data completeness for the paediatric prevalent ERF population on 31/12/2015

		% completeness				
Centre	*N*	First seen date	Height at RRT start	Weight at RRT start	Creatinine at RRT start	Primary renal diagnosis
Blfst_P*	25	92.0	80.0	88.0	92.0	100.0
Bham_P*	110	93.6	92.7	94.6	94.6	99.1
Brstl_P*	56	96.4	87.5	94.6	98.2	100.0
Cardf_P	31	93.6	96.8	96.8	96.8	100.0
Glasg_P*	56	100.0	96.4	100.0	98.2	100.0
L Eve_P*	100	84.0	60.0	66.0	68.0	100.0
L GOSH_P*	179	96.7	88.3	93.9	96.1	100.0
Leeds_P*	82	100.0	90.2	100.0	100.0	100.0
Livpl_P	56	94.6	69.6	76.8	91.1	96.4
Manch_P*	91	94.5	92.3	95.6	95.6	100.0
Newc_P*	36	100.0	97.2	97.2	100.0	100.0
Nottm_P*	87	95.4	73.6	89.7	87.4	94.3
Soton_P	32	93.8	50.0	50.0	59.4	100.0
UK	**941**	**94.8**	**83.4**	**89.3**	**91.2**	**99.2**

RRT – renal replacement therapy
*Denotes centre undertaking kidney transplantation for children

Table 4.2. The UK paediatric prevalent ERF population <16 years old on 31/12/2015, by age group and gender

	All patients		Males		Females		M : F rate ratio
Age group (years)	*N*	pmarp	*N*	pmarp	*N*	pmarp	
0–<2	21	13.4	13	16.2	8	10.5	1.5
2–<4	55	33.5	40	47.6	15	18.7	2.5
4–<8	185	57.2	126	76.1	59	37.3	2.0
8–<12	231	77.2	143	93.3	88	60.2	1.5
12–<16	277	98.1	172	118.9	105	76.2	1.6
Under 16	**769**	**62.7**	**494**	**78.7**	**275**	**46.0**	**1.7**

pmarp – per million age related population

Table 4.3. The UK paediatric prevalent ERF population <16 years old on 31/12/2015, by age group and ethnic group[a]

	White		South Asian		Black		Other[b]
Age group (years)	*N*	pmarp	*N*	pmarp	*N*	pmarp	*N*
0–<4	52	20.1	11	52.2	2	23.7	9
4–<8	132	55.2	25	128.2	3	38.5	21
8–<12	163	63.7	46	220.7	8	95.9	12
12–<16	200	74.2	43	195.8	16	182.1	16
Under 16	**547**	**53.5**	**125**	**149.9**	**29**	**86.9**	**58**

pmarp – per million age related population
[a]Ten children with no ethnicity data recorded are excluded from this table
[b]pmarp data not included for group 'Other', because the group is too heterogeneous

patients, as shown in table 4.4. There were no transplants in those aged under two years and live transplants were more common than deceased transplants in those aged two to under 12 years. Treatment in the youngest age groups was subject to variation because there were few patients. There was no difference in modality by gender or ethnicity.

Cause of ERF

Renal dysplasia with or without reflux nephropathy was the commonest primary renal diagnosis (PRD) in prevalent patients under 16 years in 2015 as shown in table 4.5. The high male to female ratio in those with obstructive uropathy was a result of posterior urethral valves. Figure 4.3 displays the percentage of patients in

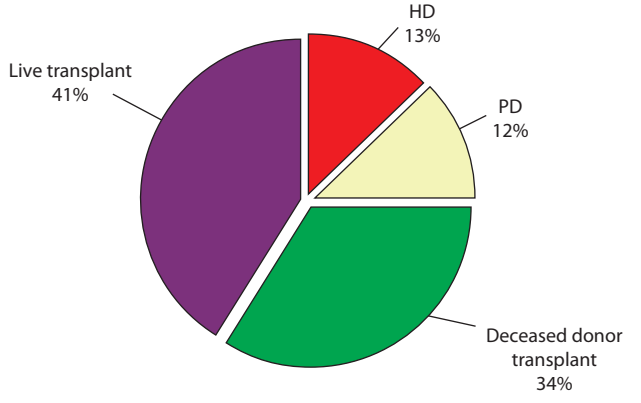

Fig. 4.1. RRT treatment used by prevalent paediatric patients <16 years old on 31/12/2015

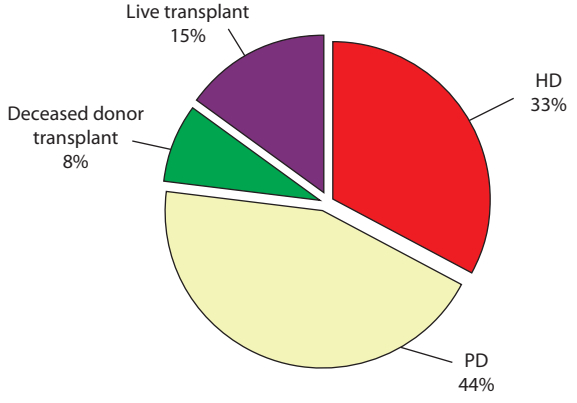

Fig. 4.2. Treatment modality at start of RRT in prevalent paediatric patients <16 years old on 31/12/2015

Table 4.4. Current treatment modality by age group in the UK paediatric prevalent ERF population <18 years old on 31/12/2015

Age group (years)	Total	Current treatment							
		HD		PD		Live transplant		Deceased donor transplant	
		N	%	*N*	%	*N*	%	*N*	%
0–<2	21	5	23.8	16	76.2	0	0.0	0	0.0
2–<4	55	16	29.1	24	43.6	13	23.6	2	3.6
4–<8	185	25	13.5	18	9.7	102	55.1	40	21.6
8–<12	231	30	13.0	14	6.1	97	42.0	90	39.0
12–<16	277	24	8.7	18	6.5	108	39.0	127	45.8
16–<18	172	9	5.2	10	5.8	68	39.5	85	49.4
Under 16	**769**	**100**	**13.0**	**90**	**11.7**	**320**	**41.6**	**259**	**33.7**
Under 18	**941**	**109**	**11.6**	**100**	**10.6**	**388**	**41.2**	**344**	**36.6**

HD – haemodialysis; PD – peritoneal dialysis

Table 4.5. Number, percentage and gender by primary renal disease in the UK paediatric prevalent ERF population <16 years old on 31/12/2015*

Diagnostic group	*N*	%	Males	Females	M : F ratio
Renal dysplasia ± reflux	267	34.7	172	95	1.8
Obstructive uropathy	145	18.9	142	3	47.3
Glomerular disease	88	11.4	37	51	0.7
Congenital nephrotic syndrome	77	10.0	40	37	1.1
Tubulo-interstitial diseases	51	6.6	21	30	0.7
Renovascular disease	37	4.8	25	12	2.1
Polycystic kidney disease	33	4.3	15	18	0.8
Metabolic	29	3.8	18	11	1.6
Uncertain aetiology	19	2.5	13	6	2.2
Malignancy & associated disease	17	2.2	5	12	0.4
Missing	6	0.8	6	0	
Total	**769**		**494**	**275**	**1.8**

*In 2015 there were no patients with ERF secondary to 'drug nephrotoxicity'

each diagnostic category for incident and prevalent cohorts. Missing PRD data have remained low: 0.4% in 2011 [4] to 0.8% in 2015.

The commonest comorbidities at the onset of RRT in 2015 were congenital abnormalities, developmental delay and syndromic diagnoses, reported in 7.0%, 6.9% and 6.5% of patients respectively, as shown in table 4.6. Although the majority of children were reported to have no comorbidities, there was considerable variation between centres (e.g. no comorbidity reported in 94% of patients from Cardiff and 50% of patients from Bristol). This may be due to small numbers in some centres or reporting practice and will be subject to a data quality exercise to evaluate whether there are genuine differences between centres in their willingness to accept patients with comorbidities onto the RRT programme.

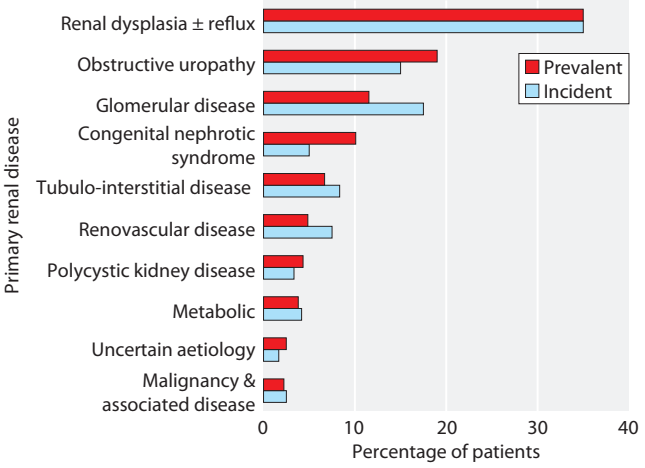

Fig. 4.3. Primary renal disease percentage in the UK paediatric incident and prevalent ERF population <16 years old in 2015 for patients with a reported causative diagnosis

Table 4.6. Frequency of registered comorbidities at onset of RRT in the UK paediatric prevalent ERF population <16 years old in 2015

Comorbidity	*N*	% all RRT patients
Congenital abnormality	54	7.0
Developmental delay	53	6.9
Syndromic diagnosis	50	6.5
Prematurity	46	6.0
Consanguinity	26	3.4
Liver disease	12	1.6
Chromosomal abnormality	11	1.4
Family member with ERF	11	1.4
Cerebral palsy	8	1.0
Congenital heart disease	7	0.9
Malignancy	6	0.8
Neural tube defect	4	0.5
Psychological disorder	4	0.5
Diabetes	1	0.1
No reported comorbidity	**571**	**74.3**
One reported comorbidity	**128**	**16.6**
Two or more comorbidities	**70**	**9.1**

The UK paediatric incident ERF population in 2015

There were 137 patients <18 years of age who commenced RRT at paediatric renal centres in 2015. As before, the following analyses were restricted to the 125 patients who were <16 years of age.

The incidence of RRT was 10.2 pmarp in 2015. Patients commencing RRT in 2015 are displayed by age and gender in table 4.7; apparent differences may be a result of small group sizes.

Trends in ERF demographics

Table 4.8 shows that the reported incidence of RRT has remained steady since 2001, with the highest incidence seen in both the youngest and oldest age groups. There were 1,715 children and adolescents <16 years of age who had received RRT in the UK over the 15-year period between 2001 and 2015. Table 4.9 shows an increase in the proportion of those aged two to <four years starting RRT and a decrease in the proportion of those aged 12 to <16 years starting RRT over the time period. Table 4.10 shows a decrease in the proportion of those with a White ethnicity starting RRT and an increase in the proportion of those in the 'Other' ethnic group starting RRT over the time period. Table 4.11 shows that the overall proportions between paediatric renal centres have fluctuated only slightly over the time period.

Table 4.8. Reported average incidence by age group in five-year time periods of the UK paediatric incident ERF population <16 years old commencing RRT

Age group (years)	pmarp		
	2001–2005	2006–2010	2011–2015
0–<2	12.4	13.1	12.1
2–<4	5.8	7.3	9.4
4–<8	5.7	6.9	6.9
8–<12	8.1	8.9	9.5
12–<16	13.1	14.4	11.7
Under 16	**9.1**	**10.2**	**9.7**

pmarp – per million age related population

Table 4.12 shows the number and percentage of children receiving RRT with each of the major reported comorbidities over the last 15 years. As before, any apparent differences may be a result of small numbers between groups. Overall, less comorbidity has been reported in children receiving RRT over the last 15 years and, as previously mentioned, it is not clear whether this was due to reporting or differences in case selection.

The proportion of those starting RRT with deceased donor transplants is falling (from 12.0% in 2001–2005 to 8.6% in 2011–2015), as shown in figure 4.4, whilst

Table 4.7. The UK paediatric incident ERF population <16 years old in 2015, by age group and gender

Age group (years)	All patients		Males		Females		M : F ratio
	N	pmarp	*N*	pmarp	*N*	pmarp	
0–<2	22	14.1	16	20.0	6	7.9	2.5
2–<4	14	8.5	10	11.9	4	5.0	2.4
4–<8	34	10.5	21	12.7	13	8.2	1.5
8–<12	26	8.7	14	9.1	12	8.2	1.1
12–<16	29	10.3	17	11.8	12	8.7	1.3
Under 16	**125**	**10.2**	**78**	**12.4**	**47**	**7.9**	**1.6**

pmarp – per million age related population

Table 4.9. Number and percentage of the UK paediatric incident ERF population <16 years old who commenced RRT, by age group and five-year period of starting RRT

	2001–2005		2006–2010		2011–2015	
Age group (years)	*N*	%	*N*	%	*N*	%
0–<2	83	15.6	101	16.9	98	16.8
2–<4	39	7.3	53	8.9	76	13.0
4–<8	83	15.6	95	15.9	107	18.3
8–<12	123	23.1	129	21.6	133	22.8
12–<16	205	38.5	220	36.8	170	29.1
Under 16	**533**		**598**		**584**	

Table 4.10. Number* and percentage of the UK paediatric incident ERF population <16 years old who commenced RRT, by ethnicity and five-year period of starting RRT

	2001–2005		2006–2010		2011–2015	
Ethnic group	*N*	%	*N*	%	*N*	%
White	418	78.7	445	75.3	399	69.6
South Asian	81	15.3	93	15.7	102	17.8
Black	14	2.6	24	4.1	20	3.5
Other	18	3.4	29	4.9	52	9.1
Under 16	**531**		**591**		**573**	

*Two children in 2001–2005, seven in 2006–2010 and 11 in 2011–2015 with no ethnicity recorded are excluded from this table

that of live transplants has remained stable in the two most recent five-year periods (17.8%). As seen previously, use of PD as a starting modality has fallen from 53.0% in 2001–2005 to 36.8% in 2011–2015, being replaced with increased use of HD and living kidney donation.

Glomerular disease as a cause of ERF has fallen compared to other PRDs in the prevalent paediatric population over the last 15 years, as shown in table 4.13.

Pre-emptive transplantation

Of the 1,715 patients aged <16 years who started RRT between 2001 and 2015, 463 were excluded from this

Table 4.11. Number and percentage of the UK paediatric incident ERF population <16 years old, by renal centre and five-year period of starting RRT

	2001–2005		2006–2010		2011–2015	
Centre	*N*	%	*N*	%	*N*	%
Blfst_P	17	3.2	24	4.0	13	2.2
Bham_P	54	10.1	66	11.0	70	12.0
Brstl_P	41	7.7	34	5.7	32	5.5
Cardf_P	16	3.0	19	3.2	24	4.1
Glasg_P	33	6.2	44	7.4	39	6.7
L Eve_P	44	8.3	65	10.9	63	10.8
L GOSH_P	97	18.2	121	20.2	99	17.0
Leeds_P	50	9.4	53	8.9	53	9.1
Livpl_P	31	5.8	21	3.5	35	6.0
Manch_P	52	9.8	47	7.9	68	11.6
Newc_P	30	5.6	25	4.2	20	3.4
Nottm_P	47	8.8	63	10.5	47	8.0
Soton_P	21	3.9	16	2.7	21	3.6
Under 16	**533**		**598**		**584**	

Table 4.12. Trends in reported comorbidity frequency at the onset of RRT in the UK paediatric incident population <16 years old, by five-year period

	2001–2005		2006–2010		2011–2015	
Comorbidity	*N*	%	*N*	%	*N*	%
Syndromic diagnosis	49	9.2	45	7.5	31	5.3
Developmental delay	38	7.1	44	7.4	30	5.1
Congenital abnormality	48	9.0	48	8.0	29	5.0
Prematurity	26	4.9	31	5.2	27	4.6
Consanguinity	21	3.9	16	2.7	19	3.3
Family member with ERF	22	4.1	11	1.8	13	2.2
Liver disease	10	1.9	11	1.8	8	1.4
Malignancy	8	1.5	3	0.5	5	0.9
Neural tube defect	3	0.6	4	0.7	5	0.9
Cerebral palsy	9	1.7	9	1.5	4	0.7
Congenital heart disease	12	2.3	19	3.2	4	0.7
Psychological disorder	10	1.9	8	1.3	4	0.7
Chromosomal abnormality	12	2.3	20	3.3	2	0.3
Diabetes	6	1.1	3	0.5	1	0.2
No reported comorbidity	**336**	**63.0**	**419**	**70.1**	**457**	**78.3**
One reported comorbidity	**140**	**26.3**	**119**	**19.9**	**84**	**14.4**
Two or more comorbidities	**57**	**10.7**	**60**	**10.0**	**43**	**7.4**

ERF – established renal failure

analysis (92 patients due to being aged under three months, 371 due to being late presenters). Table 4.14 shows that a third of the 1,252 patients identified as being aged three months to <16 years and starting RRT between 2001–2015 had a pre-emptive transplant.

Contrary to previous reports [1], there was no significant difference in pre-emptive transplantation rates by time period ($p = 0.09$).

There remained a significant difference in pre-emptive transplantation rates, with higher rates in boys ($p = 0.002$), although this difference was less significant ($p = 0.03$) when adjusted for other factors in a logistic regression (time period, ethnicity, age at start and PRD). Pre-emptive transplantation rates were higher in White versus non-White ethnicity ($p < 0.0001$). Analysis by age at start of RRT showed that, as expected, the lowest

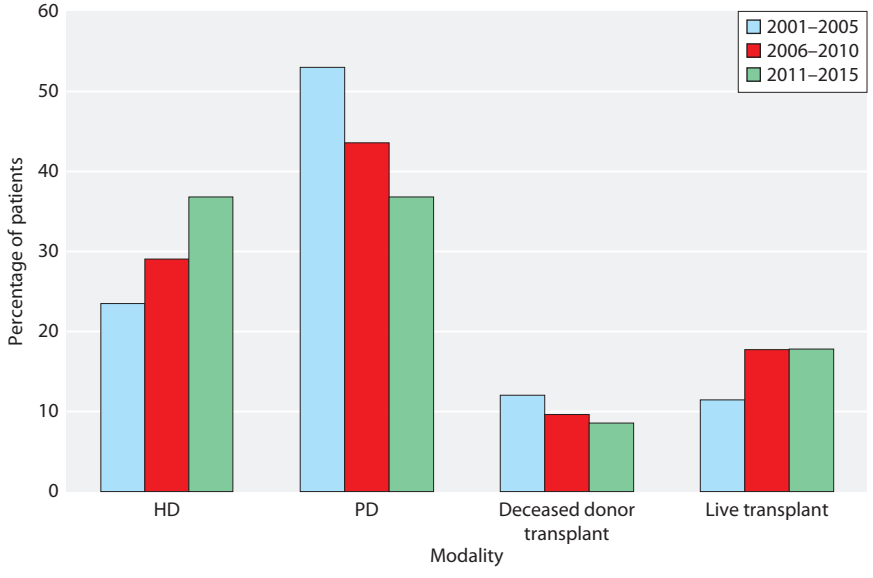

Fig. 4.4. Treatment modality at start of RRT for the UK paediatric incident ERF population <16 years old, by five-year time period

Table 4.13. Number* and percentage of primary renal diseases in the UK paediatric prevalent ERF population <16 years old, by five-year time period

	2001–2005		2006–2010		2011–2015	
Primary renal diagnosis	*N*	%	*N*	%	*N*	%
Renal dysplasia ± reflux	172	32.6	193	32.7	204	35.4
Obstructive uropathy	77	14.6	92	15.6	96	16.6
Glomerular disease	112	21.3	124	21.0	71	12.3
Tubulo-interstitial diseases	41	7.8	46	7.8	47	8.1
Congenital nephrotic syndrome	27	5.1	32	5.4	46	8.0
Uncertain aetiology	20	3.8	26	4.4	30	5.2
Polycystic kidney disease	15	2.8	14	2.4	26	4.5
Metabolic	26	4.9	30	5.1	26	4.5
Renovascular disease	18	3.4	22	3.7	22	3.8
Malignancy & associated disease	10	1.9	7	1.2	9	1.6
Drug nephrotoxicity	9	1.7	4	0.7	0	0.0

*Six children in 2001–2005, eight in 2006–2010 and seven in 2011–2015 with no primary renal diagnosis recorded are excluded from this table

rate of pre-emptive transplantation was in those aged three months to two years, whilst children aged four to 16 years had similar rates of pre-emptive transplantation. Following exclusion of the youngest age group, there was no statistical difference in pre-emptive transplantation rates by age. Rates differed with PRD (lower in glomerular diseases versus renal dysplasia ± reflux nephropathy and obstructive uropathies, $p < 0.0001$). Children with polycystic kidney disease, obstructive uropathy, metabolic causes, renal dysplasia ± reflux, uncertain aetiology and renovascular diseases had the highest rates of pre-emptive transplantation, whilst those with malignancy and congenital nephrotic syndrome had the lowest rates.

Transfer of patients to adult renal services in 2015

Eighty-five patients were reported by paediatric nephrology centres to have transferred to adult renal services in 2015, similar to the 93 who transferred during 2014 [1]. The median age of patients transferred out was 18.0 years with an inter-quartile range of 17.7–18.4 years. Table 4.15 shows that the demographics of those transferring out were very similar to those of the overall prevalent paediatric RRT population, but with 89.4% having a functioning transplant.

Survival of children on RRT during childhood

Of patients under 16 years of age, 1,561 were identified as starting RRT between 2001 and 2014 at paediatric centres in the UK and were included in the survival analyses. At the census date (31st December 2015) there were a total of 75 deaths reported in children on RRT <16 years of age at paediatric centres. The median follow up time (beyond day 90) was 3.4 years (range of three days to 14.7 years). Table 4.16 shows the survival hazard ratios (following adjustment for age at start of RRT, gender and RRT modality) and highlights that children starting RRT under two years of age had the worst survival outcomes, with a hazard ratio of 4.1 (CI 1.7–9.9, $p = 0.002$) when compared to 12–16 year olds. Being on dialysis was shown to lower survival significantly compared to having a functioning transplant, with a hazard ratio of 6.5 (CI 3.4–12.6, $p < 0.0001$). There was insufficient power to add PRD to the model; drug induced nephrotoxicity and metabolic PRDs had the worst survival but CIs were wide and included no effect. Figure 4.5 shows unadjusted Kaplan-Meier survival probabilities and highlights worse outcomes for those aged less than two years, particularly during the first year.

Mortality data in 2015

Nine deaths occurred in paediatric renal centres in 2015; the median age at death was 10.7 years (range 3.1–17.8 years). In children aged <18 years with treated ERF, the total reported mortality in 2015 in UK paediatric centres was 1.0% (9/941) and 5.5% (6/109) for those on dialysis.

Transplant deaths

In 2015, at the time of death, four children had received a kidney transplant. One child had a sudden unexplained death. The causes of death for the other three children were: malignant hyperthermia; viraemia and multiorgan failure; and an acute haematological malignancy.

Table 4.14. Demographic characteristics of pre-emptive transplantation in the UK paediatric ERF population aged three months to 16 years, 2001–2015, by five-year time period, gender, ethnicity, age at start of RRT and PRD

	N	*N* (%) pre-emptively transplanted
Total cohort analysed (2001–2015)	1,252	417 (33.3)
Time period		
2001–2005	389	115 (29.6)
2006–2010	420	155 (36.9)
2011–2015	443	147 (33.2)
Gender		
Male	791	288 (36.4)
Female	461	129 (28.0)
Ethnicity		
White	918	333 (36.3)
South Asian	207	46 (22.2)
Other	68	24 (35.3)
Black	40	6 (15.0)
Age at start of RRT (years)		
3 months–<2	134	7 (5.2)
2–<4	143	41 (28.7)
4–<8	226	93 (41.2)
8–<12	298	104 (34.9)
12–<16	451	172 (38.1)
Primary renal diagnosis		
Renal dysplasia ± reflux	438	185 (42.2)
Obstructive uropathy	226	105 (46.5)
Glomerular disease	204	25 (12.3)
Congenital nephrotic syndrome	87	4 (4.6)
Tubulo-interstitial diseases	78	16 (20.5)
Metabolic	66	29 (43.9)
Polycystic kidney disease	46	23 (50.0)
Renovascular disease	37	12 (32.4)
Uncertain aetiology	31	11 (35.5)
Malignancy & associated disease	16	1 (6.3)
Drug nephrotoxicity	5	1 (20.0)

Dialysis deaths

In 2015, at the time of death, five children were on dialysis (all HD). Two patients died due to malignancy, two due to septicaemia and another due to cardiac failure on the background of a metabolic disorder.

Discussion

This report provides the paediatric nephrology community with a unique resource of data on the demographics of the UK paediatric RRT population from the previous year, as well as allowing comparisons of trends over the last fifteen years. This information is vital for the commissioning of such a tertiary service and the data are also included in European registry reports to allow for international comparisons.

Table 4.15. Modality, gender, ethnicity and PRD of the UK paediatric ERF population <18 years old transferred out from paediatric nephrology centres to adult renal services in 2015

	N	%
Modality		
Transplant	76	89.4
HD	5	5.9
PD	4	4.7
Gender		
Male	52	61.2
Female	33	38.8
Ethnicity[a]		
White	58	69.9
South Asian	15	18.1
Other	7	8.4
Black	3	3.6
Primary renal diagnosis[bc]		
Renal dysplasia ± reflux	28	33.3
Glomerular disease	15	17.9
Obstructive uropathy	11	13.1
Tubulo-interstitial diseases	7	8.3
Congenital nephrotic syndrome	7	8.3
Polycystic kidney disease	6	7.1
Metabolic	4	4.8
Uncertain aetiology	3	3.6
Malignancy & associated disease	2	2.4
Renovascular disease	1	1.2

[a]Two children with no ethnicity recorded are excluded from this table
[b]One child with no primary renal diagnosis recorded is excluded from this table
[c]In 2015 there were no patients transferred out with 'drug nephrotoxicity'

Data returns

Paediatric nephrology in the UK faces the challenge of being mandated to submit electronic data on small numbers of patients to the UKRR, sometimes using renal computer systems designed to collect registry data for adult patients. This often results in the need for additional data collection for the paediatric-specific dataset. Overall, completeness of data items has fallen slightly. In spite of this all centres are included. Despite a standardised dataset, the extracts received by the UKRR usually require extensive input to allow them to be uploaded into the database. Once submitted data have been checked and validated they are returned to

Table 4.16. Survival hazard ratio during childhood for the UK paediatric ERF population <16 years old, adjusted for age at start of RRT, gender and RRT modality

	Hazard ratio	CI	*p*-value
Age (years)			
0–<2	4.1	1.7–9.9	0.002
2–<4	2.4	0.9–6.3	0.08
4–<8	2.7	1.1–7.0	0.04
8–<12	1.1	0.4–3.0	0.8
12–<16	1.0	–	–
Gender			
Female	1.3	0.7–2.2	0.4
Male	1.0	–	
RRT modality			
Dialysis	6.5	3.4–12.6	<0.0001
Transplant	1.0	–	

CI – confidence interval

submitting renal centres with the onus on clinicians to provide any missing data items. A system is being devised to mark unobtainable missing data and to write them off, thereby minimising requests to clinicians. Feedback on improving the process is always welcomed.

Highlights from the 2015 data

Incident and prevalent rates remained steady. Overall the prevalent population was largely White, male and predominantly aged over eight years, with a functioning transplant, although the proportion of those commencing RRT aged two to under four years and from ethnic minorities was increasing.

RRT start modality

PD remained the most frequent start modality in just under half of paediatric patients. However, since 2001, use of PD as a start treatment is falling, with pre-emptive live transplants and HD increasing. PD was still the most commonly used RRT modality in young children. It is encouraging that a third of patients are now being pre-emptively transplanted, with increased use of live transplants that rate was stable in the two most recent five-year periods. Pre-emptive transplantation was observed to be influenced by ethnicity and PRD. It is not unexpected that children and young people with, for example, glomerular disease may need to spend time on HD before transplantation is safe, but the reasons for reduced pre-emptive transplantation in children from ethnic backgrounds is unclear and needs further study.

Current treatment modality is subject to variation over time in the youngest children because of low patient numbers in those age groups. It is interesting to note that live kidney transplantation is more common than deceased transplantation in younger children, with the reverse ratio being seen in older children.

Primary renal disease

Structural renal disorders (renal dysplasia and obstructive uropathy) accounted for half of all causes of ERF. These children often present early in life, indeed some are diagnosed antenatally, so spend many years under paediatric nephrology care. Structural renal disorders are more likely to be transplanted pre-emptively, so perhaps we should be expecting to transplant a

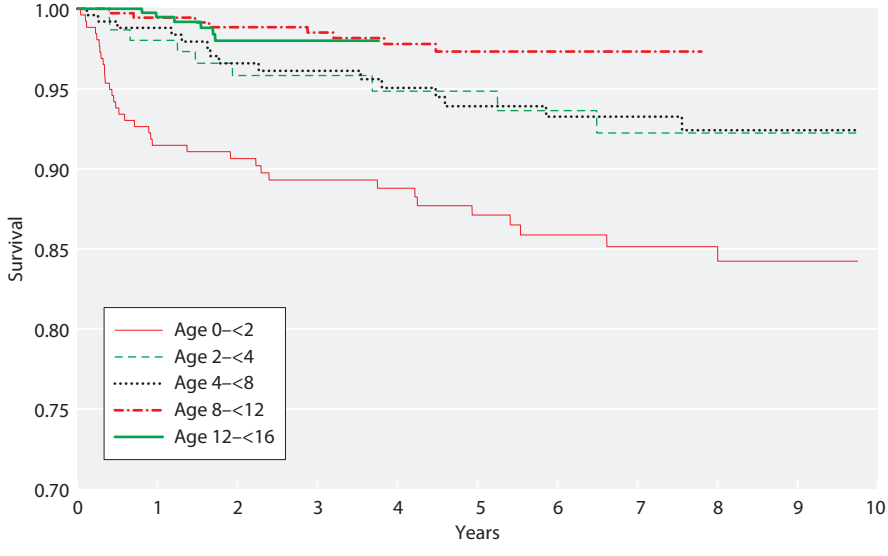

Fig. 4.5. Unadjusted Kaplan-Meier survival in the UK paediatric ERF population <16 years old starting RRT between 2001 and 2014, by age at start

greater number of children and young people pre-emptively. Some missing data may be due to a PRD not being assigned until the results of genetic tests have been received.

The proportion of glomerular disease in the paediatric RRT population has fallen by 10% since 2001–2005. With UKRR data expanding to capture earlier stages of chronic kidney disease (CKD) and resources such as the National Registry of Rare Kidney Disease (RaDaR), it should be possible to assess if better treatment is preserving renal function for longer and whether there is a corresponding increase in those with earlier stages of CKD due to glomerular pathologies.

Knowing that AKI leads to significant morbidity and mortality, the UKRR has recently contributed to work to prevent AKI nationally. Data on patients with AKI are requested by the UKRR, but most paediatric units are not yet in a position to provide those data, which would help determine the contribution of AKI to ERF. The current definitions of PRD do not pick up the contribution of AKI; often the cause of ERF is multifactorial rather than related solely to the underlying renal condition.

The incidence of renal disorders was higher in the Asian, Black and 'Other' groups compared with White. It would be interesting to look at PRD in these groups to see if there are differences in renal diseases causing ERF between populations.

Determining the representativeness of the comorbidity data could be addressed by confirming patient comorbidity data with each centre using the 2015 data. On the whole, it would appear that most paediatric patients start RRT without comorbidity, but it is known reporting varies by centre. It may be helpful to clarify the definitions of comorbidities to aid more standardised reporting.

The proportion of transplanted patients transferring to adult services remained consistently high at approximately 90% and underpins the need for well-planned transitions and transfers to ensure maximal long-term graft survival.

Survival analysis continued to show the negative influence of young age and dialysis modality. The relatively small numbers of deaths on RRT will allow a more detailed audit of deaths of children and young people on RRT. Individual units will be contacted and asked to provide more detailed information. This may help to develop more informative cause of death categories. A project using UKRR data has involved further survival analysis on a cohort of adolescents and young adults starting RRT. This project has highlighted the importance of transplant listing status on survival and the results will be published shortly.

Current and future work

Several projects are planned for the forthcoming year. A more detailed audit of deaths will be undertaken as described above. Similarly, the need for better comorbidity reporting has been discussed. Further planned work includes a report evaluating demographic and clinical factors associated with graft function post transplantation (evaluated as estimated glomerular filtration rate (eGFR)). An extended follow-up of a previously reported cohort of children who commenced dialysis aged under two years is also planned. This will provide more relevant data with five to 10 year outcomes of UK children.

Centres will be contacted with the aim of completing comorbidity and disability data for prevalent patients where this may have been submitted unclearly making it impossible to differentiate between a condition being not present in the patient or this information not being available at the time of submission. Once complete it will be possible to comment with more confidence if there are inter-centre differences in the rates of offering RRT to patients with additional comorbidities.

There is well-documented unexplained between centre variation in access to the waiting list, time taken for activation and receipt of a transplant once activated in both adult and paediatric units. Following on from the success of the Access to Transplantation and Transplant Outcome Measures (ATTOM) project in adults, the Access to Transplantation and Transplant Outcome Measures In Children (ATTOMic) project will begin by focusing on these aspects within paediatric nephrology centres, initially based on the work of declined deceased donor organs for prospective paediatric renal transplant recipients. The first stage will be for a questionnaire to be completed by the paediatric nephrologist or team caring for any child (aged <18 years) (i) on chronic dialysis; (ii) renal transplant recipient but with eGFR ≤ 30 ml/min/1.73 m^2; or (iii) CKD with eGFR ≤ 30 ml/min/1.73 m^2. Data will be requested for all prevalent children at each of the 13 paediatric nephrology centres on the census date of 31st December 2016.

The expansion of UKRR data collection to include CKD and AKI will widen the scope of our report and give insights into such questions as whether PRD proportions (for example glomerular disease, seen to be falling in the ERF population) are changing due to improved

management, delaying progression to ERF, as well as the impact of AKI on CKD disease progression.

Acknowledgement

Thanks are expressed to Kidney Research UK and the British Kidney Patient Association whose contribution through the Tony Wing award contributed to the production of this chapter.

Conflicts of interest: the authors declare no conflicts of interest

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